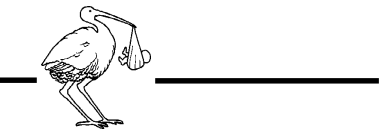
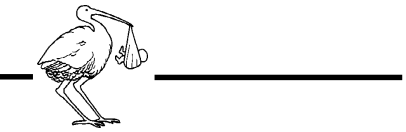
t, may I refuse to have done?

es parents the right to refuse the sts for their baby if this testing n their religious beliefs or this is true for you, be sure to tal staff or your health care



n I get more information born screening?

ormation, talk with your health r or contact the Newborn ogram using the information the front of this pamphlet.



aby be screened for other ?

on of hearing loss can lead to eech and language skills. Many offering this screening for

here are other rare disorders that ted in the newborn period.

ormation speak with your baby's rovider.

Privacy Practices

The Department of Health is required by law to protect the privacy of newborns and their families and assure that all specimen/information forms submitted for screening are protected from inappropriate use or access. A brief summary of the law's requirements are provided below. Specific requirements are described in Section 246-650-050 WAC. Copies are available upon request or on our website www.doh.wa.gov/nbs.

Newborn screening specimen forms are kept in secured storage at the State Public Health Laboratories for 21 years in accordance with Chapter 70.41.4190 RCW. After that time, specimens are destroyed. The Department of Health will destroy a specimen prior to 21 years upon receiving a written request from a parent or guardian and after all required testing has been performed.

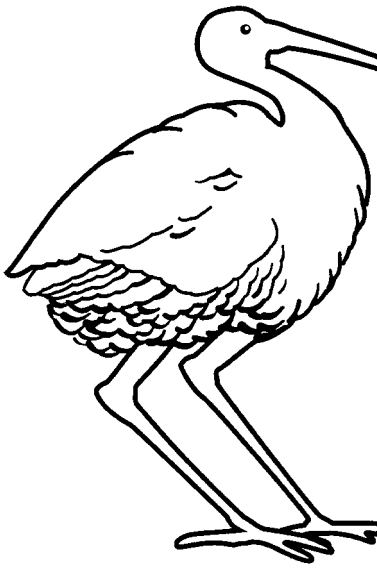
Access to newborn screening specimen forms is restricted to Department of Health personnel and approved individuals who agree to strict confidentiality requirements. Written parent consent is required for any research involving identifiable information and for most other purposes. Any release of specimens or other information must comply with the State's Uniform Health Information Act (Chapter 70.02 RCW) and the privacy and security provisions of Chapter 246-650 Newborn Screening.

There is only one charge per infant for the screening. Additional specimens are tested at no additional charge. However, your health care provider may charge a fee to collect the specimen. Diagnostic testing, if needed, will involve additional costs.

This pamphlet is available in: Cambodian, Chinese, Korean, Laotian, Russian, Spanish, and Vietnamese.

For people with disabilities, this pamphlet is available in an alternative format on request. To submit a request please call 1-866-660-9050.

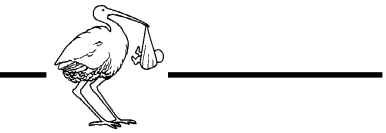
Newborn Screenin Tests & Your Bal



Newborn Screening Program
P.O. Box 55279
1610 NE 150th Street
Shoreline, WA 98155-0729
Phone: (206) 361-2902
1-866-660-9050
FAX: (206) 361-4996
Email: NBS.Prog@doh.wa.gov
Website: www.doh.wa.gov/nbs

ewborn screening?

reening is a way to identify are at risk for serious disorders table, but not apparent at birth. quires that all babies born in be tested for nine disorders are discharged from the hospital .83 RCW). Although the law abies born in hospitals, it is hat babies born outside of a eive the same quality of care.



sting important?

identifies disorders that, if not d treated, can result in mental severe illness or even death. A by may look perfectly healthy e a serious disorder. Finding ms early and treating them events many serious ns. Fortunately, treatment is prevent or greatly reduce the ese disorders.

reening tests are one important ide your baby with the best alth care. A simple blood test u and your baby's health care ormation about your baby's ou may not otherwise know.

How is testing done?

All tests are done from a few drops of blood taken from your baby's heel. The blood is collected on a special absorbent paper and sent to the State Public Health Newborn Screening Laboratory in Shoreline for testing. The hospital or health care provider that submitted the specimen is notified of the results within a few days.

What disorders are detected?

Babies are tested for the following nine disorders:

- Biotinidase deficiency
- Congenital adrenal hyperplasia (CAH)
- Congenital hypothyroidism
- Galactosemia
- Hemoglobinopathies (including sickle cell disease)
- Homocystinuria
- Maple syrup urine disease (MSUD)
- Medium chain acyl-coA dehydrogenase deficiency (MCADD)
- Phenylketonuria (PKU)

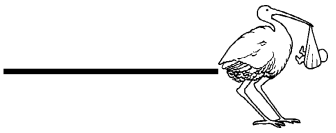
When should testing be done?

The law requires that the first specimen be collected before hospital discharge, but no later than 5 days of age. This allows affected infants to be treated as soon as possible. The routine second specimen should be collected between 7 and 14 days of age, but it is still beneficial for older babies. Additional testing should also be done when requested by your baby's health care provider.

Why are two specimens rec

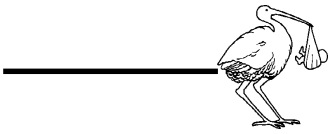
Most of the disorders will be dete first specimen, even if taken on th The second specimen is recomme some disorders may not be detect baby is slightly older.

Sometimes more than two specim requested. This does not mean y one of the disorders. The most co for requesting an additional speci previous results were inconclusive



What happens if a disorder

If the newborn screening test indi problem, your baby's health care contacted immediately. Further te recommended so treatment can b if your baby is affected with one



How can I find out the resu

If you have questions about the r your baby's screening tests, pleas health care provider. If your heal provider does not have the result should contact the Newborn Scre to obtain a copy.